

GIVING VOICE: ASSISTIVE TECHNOLOGY AND FC

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I have been using motor support, facilitated communication, as one method of providing access to communication technology for people with limited speech since 1979. That's the year I met Jamie. He was three years old, with severe cerebral palsy, a seizure disorder and no speech. Most three year olds never stop talking. They have mastered the basics of learning their language. They are exhilarated with the power. I worried about what would happen to Jamie if he could not enter the dialogue of language soon. He was already becoming a "behavior problem", communicating with his body and "oppositional behaviors" because he could not use language.

Some professionals told me that there were communication devices that talked, using synthesized speech output. These machines had been developed for adults who were nonspeaking or who had lost speech due to brain damage. The devices could give them an immediate voice. I wanted this for Jamie. It was difficult to find a speech therapist who was willing to lend me the communication devices to try out with a preschooler. Most followed the dictates of Howard Shane (1980) who argued that a toddler or preschooler must thoroughly fail at developing oral speech skills for several more years before being given a voice through technology. Otherwise, Shane hypothesized, the child might lean on the technology like a crutch and never learn to talk. (More recently, Shane is one of the speech therapists who has opposed FC most vehemently.)

I wanted Jamie to have communication technology that functioned more like a high-speed, motorized wheelchair than a crutch, so that he could out-talk all the professionals who would try to hold him back, doing wheelies on the way. Someone lent me four devices that I tried with Jamie; two devices had speech output, and two just had visual displays. Jamie wound his body around the smallest device with speech output. He had to be pried off at the end of the session. The consumer had made his choice clear.

Jamie quickly chose 15-20 messages, nodding "yes" when we guessed exactly what he wanted to say. He was able to activate many single-switch messages independently. But soon he wanted to combine words and phrases in sequences to make many different messages. Because of his cerebral palsy, he needed support at the hand or elbow to precisely construct messages. FC gave Jamie the motor support he needed to access the device.. Speech output gave him a voice.

Children and adults with limited or no speech should always be given the choice of using technology as part of being introduced to FC. Those who already use FC should be shown communication technology and be given the option to use it. In this article, I give some reasons why I consider advocating for technology to be an integral part of the fight to establish facilitated communication. Then, I talk about what my research has shown are effective ways to teach children and adults to use communication technology.

Why give people without speech a voice through speech output?

A major part of my work is to carry out assistive technology evaluations. Often I work with people who

have never facilitated. I introduce them to FC and to technology that can give them a voice in the same sessions. At other times, I am asked to assess people who have facilitated for several years. Many of these people have stopped facilitating. The wonderful professionals who made FC available to these people did not offer a voice as part of the package.

During my assessments, I show the consumers how to use letter boards, communication devices and computers with speech output. Only one person I have evaluated has not immediately chosen to use speech output through a communication device or a computer while they facilitated. Within six months, that young woman asked me to come back and do a technology evaluation with her. She said she was ready to have a voice because she wanted to talk with her friends. So, the first reason to offer technology as part of FC, in my experience, is: *When people without speech are given a choice, they choose speech output.*

Ryan, who is 22 years old and nonspeaking due to cerebral palsy, says "Technology gives me speech. It's very important because I have to talk. And without that I wouldn't be alive". He says, "Augmentative communication is a matter of life and death to people who can't talk easily. If you don't have it, you're dead. Without it, I am not alive". Ryan feels this strongly: he has experienced the fact that: *Technology provides access to independent speech and conversation*

Ryan communicates completely independently with his device. He does not require facilitation. However, when his Liberator communication device goes down and he has no speech output, he becomes dependent on someone else reading what he points to on his letter board. That is, he functions like most people who use FC without speech output. At those times, the stress on his parents is enormous. Rather than just listening and responding to Ryan, they have to stand over the letter board and read what he points to, letter by letter. Ryan and his family regard loss of his speech output as an emergency to be solved immediately. With his speech output, he takes charge of his own life: *Technology is necessary for independent living*

Ryan describes how he functions using his communication device: "With it, I can give talks at conferences. I can argue with my parents. I can use the phone to talk to people, order my own transportation without anybody in the room. I can hold a job. I have had three paying consultant jobs in the past three months".

Ryan would not have had those jobs, without speech output. His visual skills were not strong enough for him to learn to read and write based on seeing and producing text alone. He needed to become literate to be a competent communication device user - he would always need to spell at least a few words in most sentences he said with his device. For the first five years at school, he made little progress in literacy skills and was described by his school as "resistant to written expression". Since his spoken (auditory) language skills are a strength, he needed the visual signal of text to be linked with speech output for it to make sense to him. With speech output, after only 48 hours of writing on a computer, he became fully literate. *For people with poor visual skills, technology with speech output links writing to speech.*

Writing with speech output also works for people with stronger visual skills and poor, or no, spoken (auditory) language skills. Patrick, who was first facilitated at age 42 while a resident at a state institution, had visual literacy, but did not link writing to spoken language. He was autistic and completely nonverbal. He decided that writing with speech output could help him learn to understand speech and even to talk. During one session, he facilitated, "Understand how I may talk. How I can talk is I first write it and then I read it (with speech output). I can read how to say it. I can make the machine say it". He saw speech output as a tool that would link his visual/written language skills to the spoken language he heard around him. The more he was able to understand what was said, the more likely he

was to learn how to speak himself. My research and individual case studies have shown that *writing with speech output can lead to independent speech, better comprehension of spoken language and development of literacy skills.*

Q. Why don't more people without speech have a voice through technology?

A. Money.

Technology to give someone a voice is not cheap. Often, professionals who facilitate do not want to bring up the issue of technology. Institutions are threatened by the cost of providing voices through technology to the many people without speech that they are supposed to serve. They complain that if one person gets a voice, everyone will want one. We must never forget that freedom of speech is a basic civil right guaranteed by the Constitution, as well as a reasonable accommodation required by the ADA. Motorized wheelchairs are no longer seen as luxuries. Communication technology is at least as necessary to people without speech, if they are to function as full members of society. Someone at a recent conference asked Ryan whether speech output was really necessary, wouldn't just a visual display of his messages be adequate? He gestured his frustration with the questions, then, responded, "Look, when you need something, you just need it".

How do you give people without speech a voice through speech output?

Most assistive technology evaluations are set up for failure. Most professionals who work with children and adults with disabilities are not trained in implementing assistive technology. Consumers are often referred to centers that specialize in technology. They "evaluate" what a person can do on a particular day, spending 20 minutes to two hours in a single session, then, give the person the device that they can independently access and use that day. Most assistive technology centers do not allow the use of FC during assessment. The consumer is sent home with no additional teaching about how to function in this new role as a person with a voice. Family, friends and support staff are not given enough teaching to know how to help the person with disabilities use the technology to achieve their goals.

What, then, are the characteristics of an effective assistive technology evaluation? To begin with, at least 4 sessions, lasting at least 1 hour each are needed to:

1. Determine which technology matches the consumers abilities (current and potential), lifestyle and goals. Examples: Does the person want/need to walk around the community carrying the device, or can the device be mounted on a wheelchair ?; Is the consumer literate or will the consumer need teaching to become literate?; Will the consumer just be talking with friends or giving speeches in the community?; Does the consumer want to print messages?
2. Show the consumer some devices that will meet these requirements.
3. Determine what the consumer needs to talk about, what words, phrases, messages and speeches are most immediately needed.
4. Teach the consumer how to use some devices to express those meanings.
5. Write a report working with the consumer detailing: choice of technology and reasons for the choice, a detailed plan for the consumer to learn to have a voice, a plan to strengthen spoken and written language skills, and a plan to learn to use the voice with family, friends, staff and community. Specific support staff and number of hours should be identified in the report.

Many people with limited speech who need assistive technology have not been included in the planning

of lifestyle and goals - they have no way to communicate. The assessment must include giving someone a voice and then asking THEM what they need the technology for (talking on the phone, a job, talking to people in the community, taking notes in class, etc.). The consumer should be shown all available choices, rather than having a staff person make choices without showing them. When a speech therapist decides to use assistive technology with a student they usually try a behavioral approach. The staff decides what the consumer needs to say (usually greetings, basic needs and some vocabulary as a test to "see how smart" the student is). One of my students, a 16 year old with Down syndrome and autism threw her device at the speech therapist who had put the words BLUE, YELLOW, SQUARE and CIRCLE on her device. She hadn't waited 16 years for a voice to prove to a speech therapist that she knew vocabulary for colors and shapes. Then, they said that she had failed her assistive technology evaluation. Now, she uses her voice to constantly say, I LOVE YOU, DAD. She definitively ends her sessions which take place at 6:00 in the evening, by saying, I'M FINISHED, LET'S GO, COME WITH ME, I WANT+A HOT DOG, I'M HUNGRY, IS IT TIME TO EAT?.

I work cooperatively with my students to come to a decision about what technology will work best with them. We try constructing the same messages on the various devices. For example, Sue decided that she needed a communication device after six years of facilitation on devices without speech output. She has extremely limited speech skills due to autism. She facilitates with a high level of independence, only requiring physical support at the shoulder or elbow in many contexts and no support in others. During her evaluation, she worked on a laptop and a desktop computer writing with speech output, but chose the LightWriter communication device, saying, "This awesome device is the one I really really want. I like the voice output, the small size and the screen on both sides. I can now talk to my friends". Although Sue has just started attending college, she chose not to take her own notes on a laptop computer during classes at this time, but to have her aide take notes, while she concentrates on communicating through the device. Talking with her friends is her highest goal now. Note-taking can wait.

Karen, who is 34 years old, is also autistic. She still needs motor support at the hand or wrist. During her evaluation, she thought at first that she wanted a small portable communication device, saying, "I want a communication device. sad i want tell people i am here. i am smart. speech out. i want speech output. spell on it. go get it". However, as she compared using a laptop computer with working on the communication device, she decided she needed a computer, saying, "i can talk on the computer. talking is wonderful. lots is told. I want a computer. I told you I would like to take reading classes. I want to read lots of books. I want to write. I am a writer. Laptop computer. poems. read . Karen is a writer". I asked her if she wanted to write a poem during the session, to see how it would feel writing on a laptop. She wrote how she felt about being judged as retarded for so many years because she is not able to speak: "How look at me without a wrong idea, put your ideas on me. So sad without a voice".

Another consumer, Maria, 20 years old, nonspeaking with autism, has recently chosen to facilitate. Someone introduced her to FC with a letter board years ago, but she rejected it. When I showed her she could write on a computer with speech output and have a voice, she used FC to talk to me immediately for over an hour. Once I tried to get her to use the letter board, because my computer wasn't working. She said one of the few words she has in her own speech, "Caca". When I missed a recent evaluation session, she started the next session, saying, "where were you? you have to come. talk is out with you. come talk where were you to talk to me gone to your son. no. Really out my talk. good good to talk. do you like me out to talk is good. i sound really loud. loud" . She is still deciding whether she wants a small portable device or a computer with speech output. She likes to see her words on the computer screen and to print out her writing, but she also would like to take her voice with her to see family, to church and into the community.

Giving a voice to young children

With young children, who are just beginning to develop literacy skills, I always provide an immediate voice through a communication device with speech output. At the same time, I teach how to use written language to access the full generative power of language. (Generative: "I can say any new thing I want to say.") I often ask their parents to "bring their world in a bag", that is, to take a big plastic bag and dump into it anything the child pays attention to at home. Usually, they bring videotapes, audio tapes and books, stuffed animals and action figures, favorite foods and drinks. These form the basis for the first messages on the device.

Erica, a nonspeaking 8 year old with cerebral palsy, who is fully included at her school, was happy to be offered cookies by her speech therapist. She rarely gets them at home. She asked for the cookie on her communication device, by using FC with her left hand to sequence I + WANT, then, reaching over with her right hand independently to complete the utterance, hitting A COOKIE.

Erica also uses a letter board and writing on a computer with speech output when what she wants to say is not on her device. For example, one evening, Erica was tired and fussy. Someone who doubted FC had come to watch me work with her. I asked Erica what she would make her feel better. She pointed to P-L-O-W on her letter board. I told her I didn't understand, could she say it again? She pointed even more decisively, P-L-O-W. I called her mother, Eileen, in to help interpret. Erica, again, pointed forcefully and a little angrily, P-L-O-W. When we still didn't get it, she slid off the couch and crawled over to her vibrating pillow on the floor. Erica's excellent repeated error helped convince the skeptic that she really was communicating through FC.

Many young children who can't talk because of physical disabilities do not have the motor skills needed to begin to explore their worlds and play. Play and language learning are inextricably linked at the beginning stages of language acquisition. I constantly look for toys they can manipulate or things that they can tell me to do that are exciting (for example, making a helicopter blade fly off and hit the ceiling). Christopher, homebound because his lungs were damaged at birth, nonspeaking with severe CP, has a hard time using his own hands to make anything happen with toys. I have bought him some gross-looking puppets from environmental groups, including a big hairy wingless emu with bright orange eyes and a large mouth and a scaly dinosaur with big teeth, which Chris has named Snappy. His communication device lets him sequence phrases to direct how the puppets will interact with each other, his nurses (who he calls ATE, Tagolog for big sister) and me. His 32 choice AlphaTalker overlay looks like:

ME	LET ME OUT	PLEASE	YOUR BACK HURTS	TO	I LOVE YOU	BYE	I'M FINISHED
I WANT	WIND	LOOK AT	KILL	THE BUG	SPIT ON	AAARGH!	IN THE EAR
YES	ATE	MORE	COME HERE PLEASE	EAT	BIT	I'M A STINKY GORIO	THE MONKEY
NO	KISS	SPIDER	THE HATCHET	OUCH IT HURTS	THE COMPUTER	SNAPPY	EMU

With this, he can say, I WANT + EMU+ TO+ BITE+ SNAPPY. SNAPPY can say AAAARGH and OUCH, IT HURTS. Then, Chris can tell EMU to KISS+ SNAPPY to make up. But, EMU is a brat (A STINKY GORIO) and he usually SPITS ON+SNAPPY+IN THE EAR. Sometimes, Chris asks, I

WANT +EMU+TO+ SPIT ON+ME+IN THE EAR. Then, Chris says, I WANT + THE HATCHET +TO+KILL+EMU. Often, the play results in something that Chris can't say on the device, so he asks for the computer. Recently, for example, he typed, "Snappy has Emu spit up his nose". Literacy is giving Chris the generative power of language he needs.

No matter what disabilities a child has, it is possible to create play that can be talked about using speech output. Both Erica and Christopher are now exploring the Vanguard, a new device that lets the child create and switch to hundreds of levels of personally meaningful displays, similar to the one above, with graphics, on an active matrix screen. It is also possible to go to spelling (with text to speech) and Minspeak on this device. Minspeak is the best software available for reducing the number of keystrokes necessary to construct a message. When Ryan started using Minspeak, he went from a rate of typing 4 words per minute to being able to produce 18-22 words per minute, with 72 hours of teaching. Because of the multiple levels, children can use the Vanguard to talk to their aides, do schoolwork, participate in class, play games with peers, choose how to take a break, and request more or less facilitation.

Don't forget independence: Let people chose when and if to facilitate and use technology

Art was 19 years old, with autism and the speech skills of a 2-3 year old when I met him. People had tried to use FC with him, but he refused. He disliked being touched. He could read at the third or even fourth grade level, but his written language skills were extremely limited, because handwriting and printing were as difficult for him as for most people with autism. He wanted to learn to write independently on a computer. He liked hearing speech output for the letters, words and sentences as he wrote.

My research has shown that helping students with limited spoken language write age-appropriate grammatical sentences about personally meaningful topics can generalize to their being able to speak spontaneously in grammatical sentences. At baseline, Art's spoken utterances included, "wedy wote" for "I already wrote," and "the king, put he in rocket take he, the king, to Pluto", meaning "We will put the king in a rocket and take him to Pluto". After 48 hours of writing on the computer (2 times per week for 6 months), his spontaneous speech included, "After this, my dad will give me my allowance and I will save up to go to Universal Studios". Now, he is concentrating on the language structure for questions and negatives, by writing questions and negative sentences. Last week, he spontaneously said, "Dad, how much does it cost to go to Universal Studios?". For a class assignment he wrote, "The eagle in me can soar, high in the sky. .. The eagle in me is not afraid. He is beautiful with blue eyes, a yellow beak and white feathers on his face. The eagle in me is not alone. I fly with other eagles".

Finding, supporting and honoring the choices of nonspeaking people with disabilities is the most important part of this work. Eugene Marcus, a man with autism, eloquently wrote about the importance of choice in an earlier issue of the *FC Digest*:

Please know that every person who struggles can find his own way to succeed; but only that way which he chooses for better or worse as his own way will make both his successes and his failures truly his accomplishments. When I finally become an independent liver, it will be because that is the path I chose many years ago. If I had not decided to be that kind of person, my progress would have led me deeper into knowing my slavery, monstrous slavery, not freedom. ([Marcus, 1997](#))

Technology and teaching can give any person freedom of speech. Ryan sums up the contribution of assistive technology:

All people in this world, can, somehow, in some way, talk, no matter what!

RECOMMENDED TECHNOLOGY AND SOFTWARE	
Zygo (800) 234 -6006	LightWriter (small, very portable, writing device with DecTalk)
Prentke Romich (800)262-1984	AlphaTalker (beginning communication device) Vanguard (an intermediate message, writing, Minspeak device for school-aged children) Liberator (writing + Minspeak device)
Assistive Technology (800) 793 9227	Link, (small portable less expensive writing device with DecTalk)
Grayley Marketing (562) 947-7848	communication (letter) board sturdy plastic, some messages Computers: IBM or Macintosh (Macs have much better speech output)
IntelliTools (800) 899-6687	IntelliTalk Software (basic writing program) IntelliKeys (expanded keyboard, where needed)

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